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## Patient competence in obsessive-compulsive disorder

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2015

### **document version**

Publisher's PDF, also known as Version of record

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### **citation for published version (APA)**

Ruissen, A. M. (2015). *Patient competence in obsessive-compulsive disorder: An empirical ethical study*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

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The background of the page is a light-colored, textured fabric, possibly linen or cotton, with a visible weave. Scattered across this fabric are numerous buttons of various sizes, shapes, and colors, including white, cream, brown, and dark grey. Some buttons have visible stitching or patterns. A small, ornate silver brooch is also visible on the left side of the page.

# *Chapter 8*

Summary and general discussion



*“Hoewel de psychiatrie per sé geen rationeel vak is, is het mogelijk om het op rationele wijze uit te oefenen”<sup>18</sup>*

In this chapter the main findings from our study on competence in patients with an obsessive compulsive disorder (OCD) and their health care professionals will be summarized. Next, we will provide a theoretical reflection on these findings, going into the relevance of care ethics. After that, we will discuss the methodology of the study. The chapter ends with recommendations for future research and for clinical practice.

## **Summary of main findings**

In the introduction of the thesis, the following research questions were formulated.

- What is the state of the art regarding competence conceptualization and assessment in psychiatry, what are the current standards and how are they discussed in literature?
- What is the role of insight in competence assessment in psychiatry and how can the concept of insight contribute to adequate competence assessment?
- How is the concept of competence understood and used in daily psychiatric practice by patients with OCD, and how does this differ from current standards?
- How is the concept of competence understood and used in daily psychiatric practice by mental health professionals, and how does this differ from current standards?
- What conclusions can be drawn from a medical ethical perspective regarding the current standards regarding competence conceptualization and assessment and what recommendations can be formulated for health care professionals working with patients with OCD?

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<sup>18</sup> Vrij naar stelling behorend bij het proefschrift Fetoplacental circulation door CJ Ruissen, 1990

Against the background of the research questions, we will present and discuss the main findings. First we will go into the state of the art regarding competence conceptualization and assessment; then we will discuss the relationship between competence and insight; finally we will elaborate on the experiences of patients and professionals regarding competence.

### *Competence conceptualization and assessment*

There is no consensus about an exact definition of competence, but there is international consensus about conditions for assessment: competence is assumed until proven otherwise; it is task-specific; concerns the decision-making ability and not the decision itself; and may vary over time and may depend on the situation. A categorical approach, e.g. all patients with a certain disorder are incompetent, is obsolete.

The debate on competence conceptualization and assessment continue, but authors and stakeholders agree that if there are doubts on a patient competence and important treatment decisions are at stake, including the refusal of potential beneficial interventions, a competence assessment is relevant. A non-psychotic diagnosis, including the diagnosis obsessive compulsive disorder, is not enough to state that the patient is probably competent.

The most used tool for assessment is the MacCAT (Grisso et al., 1997), which focuses on the ability to make a choice, to understand information, to appreciate the situation, and to reason. The MacCAT is critiqued for its cognitive bias. Other factors, such as emotions and values are relevant for assessment as well. In our study other factors, such as insight, identity, and the ability to integrate various values in life proved to be of importance too, in patients with OCD. Therefore we plead for a competence assessment that is embedded in a broader process of deliberation and care to do right to the complexity of competence conceptualization and assessment.

### *Insight and competence do not overlap in OCD*

Insight is an important aspect of competence. In the standard approach, competence entails being able to appreciate the situation, that is, being able to see

that the information about the disease and the possibilities for treatment are applicable to oneself. Yet, insight is not enough. In non-psychotic disorders, patients with adequate insight can be incompetent. This is especially relevant in OCD, as it is one of the few disorders in DSM with a specifier for insight.

The patients in our study mostly met criteria for sufficient insight. All but one patient fully agreed on the diagnosis of OCD, the one that did not fully agree was ready to at least consider the diagnosis. All patients recognized descriptions of symptoms and also were able to see that those symptoms had disadvantages in one way or another. Given the importance of disorder awareness and attribution in the conceptualization of insight, most of them might have been assessed as having adequate insight. The health care professionals in our study, however, had serious doubts on their patient's competence. This is similar to findings in anorexia nervosa (Tan et al., 2006), in which insight was adequate but MacCAT outcomes were false-positive.

### *The importance of dialogue and deliberation*

Patients with OCD describe difficulties in combining values related to the disease and other values in life. Patients perceive being able to reflect on ambivalences and to find a balance between various values in life as important. The process of learning to integrate OCD in life can be characterized as a quest. In this process, the patient also develops commitment with treatment.

Mental health care professionals, when explaining competence, refer to issues which go beyond cognitive rationality, such as the possibility to have a conversation with the patient. When discussing incompetence, they refer to patients' emotions, values, and identity. Professionals can engage in the patient's quest, which empowers competence and might improve treatment outcome. A professional can facilitate and support the quest for meaning and significance in having OCD and finding and explicating values in life. They may use strategies such as a motivational approach, convincing and focusing on patients' values and identity.

Both patients' and professionals' conceptualizations of competence refer to the importance of conversation and dialogue. Support in the patient's quest requires attention for the patient's values and helping the patient to reflect on these

values. This goes beyond a paternalistic approach, since not the physician's values, but the patient's values are important. It also goes beyond the informative model, since patient's values are not taken for granted, but regarded as open to reflection and deliberation. Thus, the deliberative model of the physician-patient relationship seems most appropriate in the communications with OCD patients who have difficulties in deciding about treatment and engaging with treatment (Emanuel and Emanuel, 1992). Interventions which are in line with experiences of patients and professionals also require dialogue. Paying attention to tensions between values, and discussing them with patients, not only sheds more light on the competence of patients with obsessive compulsive disorder, but also provides a basis for interventions, such as shared decision making, personal medicine and interventions focused on persuasion rather than coercion.

### **A theoretical reflection: the relevance of care ethics**

Our main findings show that in assessing competence in OCD patients, healthcare professionals should not focus on cognitive reasoning, but on the ability to balance values and to integrate the disease in their lives. They should accompany patients in their quest, and motivate them to try new ways of organizing their lives in a meaningful way. What does this mean for patient autonomy? How can professional interventions be justified as elements of good care? Care ethics can help to answer these questions, by introducing a new concept of autonomy, that is relational autonomy, and by specifying what is morally at stake in a motivational approach, namely compassionate interference.

#### *Relational autonomy*

Care ethicists emphasize that persons are interdependent. They need the attention and support of others in order to develop and become autonomous agents. According to care ethicists, autonomy is not the same as being free from external influence (negative freedom). It entails the ability to live one's life in a coherent and meaningful way, and realize one's potential (positive freedom). This is in line with

our conclusion that a quest narrative requires interaction with others, to identify values and to come to understand their role in one's identity and life. When autonomy is defined in terms of negative freedom, a professional will not intervene nor support a patient in this process. When relational autonomy is adapted as framework, it is not only possible but even essential that professional and patient enter in a dialogue to jointly determine what is important in life (Widdershoven & Abma, 2011).

### *Compassionate interference*

From a care ethics perspective, respect for autonomy implies helping the person to become aware of what is important in life. This requires active interference (Widdershoven & Abma, 2011). Verkerk characterizes the care ethics approach as 'compassionate interference' (Verkerk, 1999). She stresses that it may be necessary to interfere with the patient's life, in order to prevent the patient from doing things which he or she will regret later. This may entail putting pressure on the patient, for instance to accept treatment, in order to prevent a situation in which the patient is no longer able to realize important values in life. This is in line with the deliberative model of the physician-patient relationship (Emanuel and Emanuel, 1992), in that the patient is stimulated to develop a new view on fundamental values, but it recognizes that fostering deliberation may entail the need to interfere and put pressure on the patient (see e.g. Widdershoven and Abma, 2011).

The notions of relational autonomy and compassionate interference may be helpful to better understand the need for and the role of support in psychiatric practice in general, and in OCD patients in particular. As such, care ethics can help to further explain our main findings and clarify the theoretical issues at stake.

## **Methodological issues**

In this section we will discuss the methodology of the study. In the first place, we will reflect on the empirical ethics approach. Next we will address the validity of the research. Finally we will go into the limitations of the study.



### *Empirical ethics*

Our study is based on a recently developed approach in ethics, called empirical ethics (Widdershoven & van der Scheer, 2008). In empirical ethics, empirical issues are input for ethical analysis. Philosophers have been criticized for their academic and theoretical approach of ethics, losing connection with practical contexts (De Vries, 1993). The ultimate aim of empirical ethicists is to improve the context sensitivity of ethics (Musschenga, 2005).

In empirical ethics, empirical data and ethical analysis are interrelated (McMillan & Hope, 2008). Empirical data are gathered guided by an ethical research question. The analysis of the data leads to new ethical insights. This implies a circle between empirical and ethical elements of the study. In our study, literature on competence, autonomy, freedom and control (originating from philosophical and ethical literature) and identity, values and personality (originating from empirical literature) served as a basis for the interview topics. Based on the analysis of the first interviews, the topic list was adapted. This resulted in a continuous process of fine-tuning. The analysis of the data led to new insights in ethical issues, for example concerning the importance of balancing various values for patient competence, and the role of deliberation and a motivational approach of the psychiatrist. A focus group was organized to provide an empirical check on these results.

In our study, we aimed to get insight in experiences of patients and professionals. Therefore, we invited interested patients and professionals by addressing psychiatrists working with OCD patients and contacting the patients' organization on OCD. We also came in contact with patients and professionals who heard from via others about the study or read about it on the internet and with patients and professionals who were struggling with competence-issues and had their own 'agenda' in participating in our project: they wanted to find a way-out in complex casuistry. We were clear about our own research aims, but gave room to their particular goals. We did not put any limitation regarding diagnosis: as long as a mental health care professional diagnosed OCD, inclusion was possible. We chose not to perform validated diagnostic interviews for research, because we wanted to know how competence was managed and assessed in daily psychiatric practice instead of in a controlled research setting.

During the study, we did not merely register existing views in patients and professionals, but invited them to reflect on issues they had not thought about before. Thus, our questions and interview style influenced the respondents. Most patients had had thoughts on autonomy, self determination or free will (in these or in other terms), but competence as a concept was often new for them. Professionals were familiar with the concept, but not in the context of OCD. By interviewing them on this issue, patients became to see the importance of competence, and professionals became aware of the role of incompetence in OCD patients. The PhD research presented in this thesis was combined with a specialization in psychiatry. As a result, some professionals addressed the researcher as psychiatrist in training, and some patients appealed to the researcher's background in philosophy. In general, this led to a more in depth dialogue on competence, and did not hinder the interaction.

### *Validity*

In order to ensure the validity of the study, various steps were undertaken. Ecological validity, which refers to the correspondence of the setting in which the research was performed and the setting in which the outcomes can be used, was secured by choosing a clinical setting without strict inclusion criteria on co-morbidity or medication regime.

Content validity refers to the junction between research questions and methodology. The aim was to obtain insight in patients and professionals experiences. Semi-structured interviews and a focus group were used for data collection, and in addition we continued with the interviews until data saturation was reached. Finally, we organized member checks to make sure that respondents recognized our interpretation.

External validity was fostered by providing a thick description of the data in the Grounded Theory part of the study. In the naturalistic case study the case was presented in a rich way, to facilitate naturalistic generalization.

### *Limitations*

Limitations of the study have been addressed in the previous chapters. To summarize: the sample size was small, but sufficient for qualitative goals. Quantative data on MacCAT and OVIS outcomes could not be used because the small sample size. Given the small size, we were not able to get insight into specific symptom dimensions.

Data collections and analysis were not performed completely parallel. Member checks on the basis of summarizing the results were done directly after obtaining interview transcription, but Grounded Theory Approach analysis and narrative analysis were started later, after about two third of the data was collected. To compensate for this, a focus group was organized after the initial analysis to validate results.

A further limitation concerns the family perspective. We had 9 interviews with family members of in total 8 patients. More than half of the patients refused to include a family member. Ellen's case, which we analysed in-depth, did not include a family member. Family data was used, but not analysed separately.

### **Implications for research**

Based on the above, we suggest some issues for future research.

#### *Disorder specific differences in (in)competence*

Given the results of our study on incompetence in OCD, and previous research on incompetence in anorexia nervosa (see Tan et al., 2003a; Tan et al., 2006; Tan et al., 2010) we may conclude that at least two (groups of) disorders do not fit in with the standard approach to competence, including standard assessment tools and guidelines. Research dementia (Vollmann et al., 2003), psychiatric clinical patients (Owen et al., 2009a), and psychiatric disorders (as opposed to somatic illnesses) (Owen et al., 2013) also reveals limitations of the standard approach. It has been argued that different disorders need different approaches (Dunn et al., 2006). Future research should sort out if this is the case, and which (groups of) disorders

need special attention and extra assessment directions, and in what disorders and illnesses the standard approach is sufficient.

### *Family and motivational interventions*

OCD places a heavy burden on partners and family members, and their responses to symptoms might influence the course of the disorder, including the effect of cognitive behavioral therapy with exposure response prevention. When care is regarded as a process in which all stakeholders are important, the family perspective should be taken into account in the conceptualization of competence, and family should be involved in competence management. Family interventions have been hardly studied in OCD. Interventions aimed at family factors in the treatment of OCD are suggested, but are not yet evidence-based (Nauta et al., 2012). The same goes for motivational interventions. These are thought to improve outcomes of exposure therapy, but evidence is not yet unequivocal (Simpson et al., 2010). Both interventions have been studied with quantitative methodologies. Qualitative research might add to the findings of these studies and help to explain the results.

### *Implementation studies*

Research on the implementation of theoretical insights on competence is needed. The interaction between empirical ethical research and implementation research has proven to be relevant in projects on fostering reflecting and change on coercion and restraint in psychiatry (Landeweer, 2013). Similar research can be done regarding competence. What is needed to make professionals more aware of new insights into competence, and help them to integrate them in their practical work? And how is this justified by the health care professionals? What are the experiences of patient with the new approach? And how does family perceive this?

## **Implications for clinical practice**

On the basis of our study, we can formulate some recommendations for clinical practice.

In the first place, instruments for competence assessment, including the MacCAT, should be embedded in a broader process of deliberation and care. Relevant issues, including emotions, values, insight and authenticity should be discussed, indicating what aspects of a specific theme adds to being competent and what aspects of that specific theme might affect competence.

In the second place, psychiatrists should focus on the process of interaction with the patient, rather than on merely assessing competence. One of the skills required is applying the right doctor-patient-relation-model (Emanuel & Emanuel, 1992). We argued that in complex OCD casuistry, including poor insight cases, a deliberative approach is useful for both assessment and management of incompetence. In the chapters some illustration of how this might work out in specific casuistry can be found.

In the third place, physicians should not merely accept a refusal of treatment, but investigate the underlying reasons and try to motivate the patient to accept help. It might be objected that patients might experience interference and pressure as negative. From the literature we know that most people who regain capacity following psychiatric treatment indicate retrospective approval, even if initial treatment wishes were overridden (Owen et al., 2009b). Patients say that not the exact nature of the compulsory treatment that was used, but the relationship with mental health care professionals and family, is decisive on how treatment is experienced (Tan et al., 2003b).

### *Eight do's and don'ts for professionals*

Based on the results of our study, we propose the following do's and don'ts for mental healthcare professionals.

1. Be aware of the importance and complexity of competence. (Chapter 2)
2. When a patient with OCD has adequate insight, don't conclude that he or she is therefore competent to make treatment-related decisions. A patient with OCD with adequate insight can be incompetent. (Chapter 3)
3. In patients with OCD, do not narrow a competence assessment to a MacCAT-assessment. Patients and psychiatrists indicate that identity and the ability to integrate values in life are more relevant for competence assessment than cognitive functions. (Chapter 4, 5)

4. When an OCD-patient is not competent to give informed consent for treatment, try to foster competence. This may include motivational interventions and rehabilitation-based intervention, including personalized medicine. Discussing values (e.g. parenthood) and other aspects of the patient's identity is relevant for both assessment and empowerment of competence. Controversial interventions, like pushing, insisting, seducing are sometimes needed. (Chapter 4, 5, 6)

5. When an OCD-patient is not competent to give informed consent for treatment, involve family, either in the process of fostering competence, or for getting proxy consent. (Chapter 4, 5)

6. Dare to engage in a process or quest with the (competent or incompetent) patient with OCD, when he or she is not committing to, doubting about or lingering with treatment. Good care does not consist of assessing (in)competence at  $t=x$ , but on a process of investigating the patient's values and offering alternative ways of dealing with the situation. (Chapter 6, 7)

7. Avoid coercion or restraint in incompetent patients with OCD. Patients stress that they need a subtle, caring approach in which they can get used to new circumstances. When there is an impasse in the treatment process, try a deliberative approach. As part of this approach, informal pressure or interfering interventions, such as assertive community treatment can be an option. All this can be part of a caring attitude with an eye for a patient's values and identity. Danger or harm or somatic disadvantage is sometimes present in OCD-cases, however, this is seldom acute. (General introduction, chapter 4, 5)

8. The absence of patient's informed consent is not a good reason to end the treatment relation. Refusal of treatment can, however, be a possible outcome of the decision-making process. The decision of refusing treatment is adequate when taken in a deliberative model, in which both professional and patient take part and are convinced that no treatment is the best option. (Chapter 4, 5, 6)